

Final Report: An Evaluation of an Interactive Social Media Website for Parents Who are Concerned about Vaccination.

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Abstract

Purpose: To build and evaluate a prototype website with interactive technologies to help address parental vaccination concerns.

Scope: Vaccine hesitancy is a growing public health issue in the United States. Internet-based social media applications are a promising new strategy to address parental vaccine concerns.

Methods: The study was conducted in 5 phases: 1) build a prototype interactive social media website devoted to vaccines 2) conduct a qualitative, formative evaluation of the website, 3) qualitatively and quantitatively evaluate the website's usability, 4) Re-design and improve the functionality of the website, and 5) conduct a survey study to evaluate the parental vaccine decision-making process, and pilot test the website.

Results: Formative qualitative assessment was completed with 55 participants and website usability was completed with 10 participants. Website layout, design, and content were modified based on formative qualitative and usability assessment of the website. A survey was administered to 443 parents and pregnant women to assess the vaccine decision-making process and preferences for vaccine information. Survey results indicate pregnancy is an important time for vaccine decision making in vaccine hesitant parents. Results also suggest that vaccine hesitant parents constantly re-evaluate their vaccine decisions. Lastly, 86 participants completed the website pilot test. Participants used the prototype website between 0 and 3 times over a six month follow-up period.

Key Words: vaccine hesitancy, social media

PURPOSE

To build and evaluate a website with interactive technologies to help address parental vaccination concerns in an integrated healthcare setting.

SCOPE

Widespread use of immunizations in the United States has led to the eradication or control of numerous vaccine-preventable diseases (VPDs), including smallpox, polio, diphtheria and measles(1). Recent trends, however, suggest that public trust in the national immunization program is eroding(2-4) . Expanding childhood immunization requirements and increased media coverage over alleged associations between vaccinations and chronic illnesses have heightened parental concerns over vaccine safety (5;6). Parents have also expressed concerns that their children are at low risk for infection and that many VPDs are not serious (7;8). Although a majority of parents choose to immunize their children, there is evidence to suggest that an increasing number of parents are choosing to either decline or delay immunizations for their children(9-11).

Physicians cite numerous reasons for parental vaccine hesitancy, including concerns about neurological effects (autism, multiple sclerosis), chronic diseases (diabetes, asthma), and sudden infant death syndrome. Physicians also report increasing parental concerns about vaccine ingredients, such as aluminum, antibiotics, formaldehyde, and mercury(11-13). These concerns may require pediatricians to spend more time discussing vaccine-related topics in routine well-child visits, leaving less time to cover other important topics, such as nutrition, development, behavior, and injury prevention. In some instances, pediatricians have dismissed families from their practices if the parents choose not to vaccinate. Pediatricians who dismiss vaccine-refusing families cite lack of shared goals and lack of trust as important factors for their decisions(14). Clearly, effective intervention strategies to address parental vaccination hesitancy are needed. These interventions should be designed to be low cost, to be broadly applicable, and to utilize communication modalities already used and trusted by parents.

One promising intervention strategy is the use of internet-based social media. Health educators are applying these technologies to engage patients and encourage open discussion through their websites (15). As an example, social media applications have been used to create online discussion and support groups for patients with illnesses such as cancer, diabetes and multiple sclerosis(16-18). The collective wisdom generated from these patient groups may provide a level of clinical awareness that cannot be obtained from any single patient or physician(16;19) .

New or expecting parents are particularly active social media users (20-22). A recent survey of 25,000 mothers showed that the percentage of mothers who regularly use social media increased from 11% to 63% between 2006 and 2009(23). In these online communities, children's health issues were the most discussed topic, and many websites (both pro- and anti-vaccination) are now using social media to convey the benefits and risks of vaccinations(8;24-26). Many of the anti-vaccination websites, in particular, use Web 2.0 technologies to disseminate erroneous information, discredit the medical community, and create fear(27;28).. The proliferation of anti-vaccination websites highlights the limitations of using social media for health information. These free-form technologies are prone to misinformation and vandalism(15;18). In many instances, the online forums are not moderated by experts, and the sources of health information are anonymous. In addition, despite their wide use, there is little direct evidence that participation in social media influences health behavior(29). Therefore, as the use of social media continues to increase, interventions designed to evaluate the relative benefit of using social media to promote health are needed(30).

To address this gap in research, we have built and evaluated an interactive, social media website devoted to vaccines. We have created a forum in which parents can access truthful, unbiased information, and discuss vaccine-related issues with other parents and pediatricians. The parent participants were active Kaiser Permanente Colorado (KPCO) members, and our multi-disciplinary research staff was responsible for creating the website content and moderating the discussion forums. We also built a mechanism by which the website activity can be linked to medical data extracted from the KPCO electronic health record. This application of health information technology will allow us to directly measure immunization behavior over time. The capability to link website activity to a well-defined, prospectively followed cohort provides a unique opportunity to measure the potential effectiveness of using social media to change immunization knowledge, perceptions and behavior.

Over the last year, we used the pilot data from this investigation to inform a behavioral health communication intervention to reduce parental concerns about vaccinations and increase immunization rates over time. This intervention is currently being evaluated as a randomized multi-site trial (R01HS021492). If efficacious, the intervention will represent an innovative and cost effective resource to improve the quality of routine well-child care.

METHODS

Our study was conducted with pediatricians and patients enrolled in the Kaiser Permanente Colorado (KPCO) health plan, a group model managed care organization that provides care to more than 500,000 members. The study was conducted in five phases. In phase 1, we designed and developed a prototype interactive website devoted to vaccines. For phase 2, we conducted a qualitative, formative evaluation of the website using focus groups with parents and pediatricians. For phase 3, we qualitatively and quantitatively evaluated the website's usability through one-on-one testing sessions with end-users. The results from phases 2 and 3 were then used to further develop and refine the website to meet the needs of end-users in phase 4. Lastly, for phase 5, we developed and administered a survey instrument to measure the parental vaccine decision-making process and preferences for vaccine information, and pilot tested the website. The study was approved by the KPCO Institutional Review Board, and informed consent was obtained from all participants.

Phase 1. Building a prototype interactive social media website devoted to vaccines

The website was designed and developed by a multi-disciplinary team of pediatricians, vaccine safety epidemiologists, behavioral scientists, risk-communication specialists, web developers and IT specialists. The development process focused on three main components: 1) Website content (expert-generated vaccine information); 2) Website design and functionality; and 3) Data collection and linkages with the EHR.

Website content

In the first 12 months of the study, our research team met on a weekly basis to generate the factual vaccine information on the website. The presentation of the information was guided by our prior qualitative work on vaccine hesitancy(31) and the Health Belief Model, a theoretical framework used to describe various health behaviors, including those related to vaccination (32-34). This factual information focused on vaccine safety, vaccine effectiveness, vaccine preventable diseases, vaccination laws, recommended immunization schedules, and vaccine ingredients. Our primary goal was to present the information in a way that helps to establish trust and credibility with parents(31). While all of the information on the website is pro-vaccine,

we used a soft tone that conveys openness and empathy. We also included descriptive information about our research team to convey dedication, commitment, competence and expertise, which can all be further emphasized through the interactive social media components described below.

Website design, functionality and social media

Our web development team designed the initial prototype to have a straightforward design. The objective was to create a resource that was both easy to use and interactive. The interactive social media tools include a blog, discussion forum, chat room, and an anonymous portal through which parents can ask questions. These technologies allow users to receive, develop, share, and actively request information in real time. Our goal was to create a resource that allows us to use the collective wisdom of parents to generate new website content and respond to their vaccination concerns in real time. Ultimately, we believe this transparent, interactive process will be viewed as a way in which the medical community has relinquished a certain amount of control to parents.

In addition to the social media technologies, we collaborated with the KPCO media relations department to produce a 30 second welcome video featuring two volunteer KPCO pediatricians. The welcome video represents the center piece of our website. Our objective for the welcome video was not only to describe the importance of immunizations, but to also acknowledge that vaccinating can be a difficult decision, that there is a lot of confusing information on vaccines, and that parents are ultimately responsible for making the health-related decisions for their children. Most importantly, the volunteer pediatricians stress that our goal is to provide a safe environment where parents can obtain accurate information, share their experiences, voice their opinions, and ask our team of vaccination experts any vaccine-related question.

Data collection and linkages with the EHR data

After the frontend of the website had been built, we focused on developing the backend so that the website could be formally evaluated using rigorous research methods. First, development team focused on building a prototype mechanism to collect and store individual-level website usage data from the parent participants. We are able to record which parents are accessing the website, how often the website is accessed, how long parents stay on the website, and how often parents post to the various interactive forums. We then used the KPCO electronic health record system to link the parents and their website usage data to their children's clinical data. This linkage, in turn, allowed us to build a process by which we can administer survey instruments to the participants that are timed to the age of their children. The survey instrument – described in more detail below – measures the parents' knowledge, attitudes and beliefs about immunizations. The parents' website usage and survey data are stored in separate databases, which can be linked to the immunization data extracted from their children's electronic health record. This linkage allows us to evaluate the website's impact on immunization behavior, which we are currently exploring in a randomized intervention trial.

Phase 2. Qualitative, formative evaluation of the website.

The objective of phase 2 was to generate qualitative data to help further develop and refine the website to meet the needs of end-user. We conducted focus groups and one-on-one interviews with a total of 23 parents and 32 providers. The parents included pregnant women, parents who accepted vaccines, parents who delayed vaccines and parents who refused all vaccines for their children. Parents and their vaccination behaviors were first identified using the

KPCO electronic clinical databases and then confirmed with medical record review. The providers included KPCO pediatricians and pediatric nurses.

The focus groups and interviews were led by two trained moderators: one to demonstrate the features of the website and the other to facilitate discussion. The moderators used a semi-structured interview guide that was developed by the research team. Each discussion lasted approximately 60 minutes, and participants were asked to provide feedback on the website design, content, layout and interactive social media features. The discussions were recorded and both moderators took detailed notes. After each discussion, the moderators reviewed the session to identify emerging themes. The data was analyzed in three stages using constant comparative and keyword in-context analyses (R21 – 57, 58, 59). The analysis was an ongoing process in which the data were analyzed as they were collected. This allowed us to modify the interview guide as needed, and make modifications to the website design as new ideas and concerns arose.

Phase 3. Qualitatively and quantitatively evaluate the website's usability

Usability testing sessions were conducted with 8 parents and 2 providers. Each session was conducted with a single end-user and lasted approximately 30 minutes. In the testing sessions, end-users were instructed to perform specific website tasks and complete survey questionnaires. As users performed the sample tasks, the moderators encouraged them to describe what they like or dislike about the website, what they find difficult or frustrating, and what they think can be improved. We also timed how long it took the users to perform each task, and calculated a completion and error-free rate (35). All of the testing sessions were both audio and video recorded. During the sessions, the moderators took detailed notes to track the length of time for each task and to document participant behavior and feedback. At the end of each testing session, user satisfaction was measured with the System Usability Scale (SUS), which is a widely used and evaluated survey tool for quantifying subjective assessments of usability (36-38). The results from the usability testing were used to further develop and refine the design and functionality of the website. Below is an example of 5 tasks that users were asked to perform in the usability testing sessions:

- 1) Your child is about to go to her next doctors visit. Her birthday is 10/1/2011. Please determine what vaccinations she is due for.
- 2) You would like to hear more about what other parents do to calm children while receiving vaccinations. Please find this discussion from other parents. Once you find the discussion, please post a comment that says, "Does breastfeeding really help after vaccination?"
- 3) Please find information about why the Hepatitis B Vaccine is given at birth.
- 4) You have additional questions about vaccinations and would like to chat with an expert. Please determine when the next live chat visit will be.
- 5) You would like to see the latest news on vaccination. Please find the new most recent news story and add a comment that says: "I would like more information about this."

Phase 4. Website re-design and modifications

Based on the results from the focus groups and usability testing, we re-designed the website and improved its functionality. Below is a summary of the modifications. Many of these modifications were completed in the first phase of our current AHRQ-funded intervention trial.

- A sliding set of pictures, questions and buttons featuring areas on the site that users might need to find first. We call this a “slider”. Each button on the slider takes the user to the webpage with more detailed information.
- Easy to navigate, tabbed content boxes covering all of the vaccine information areas that are featured on the slider. This feature allows the user to easily find information without having to scroll up and down the page.
- Softer colors and numerous pictures of racially diverse parents, pediatricians and babies.
- Special “interactive” buttons that take users directly to the forum to chat with other parents (the “Talk to parents” button) or to ask questions through the “Ask an expert” portal (the “Ask a question” button). The objective of placing these buttons on each page is to facilitate interaction.
- Up to date information from the media in a “Vaccines in the News” section, featuring current articles on vaccines
- Links under “Latest from the Blog” that lead to the newest blog posts

In addition to these design modifications, we designed a prototype online consenting mechanism to facilitate participation in our randomized intervention trial. This process now allows us to electronically identify potential participants with the electronic health record, send them emails to solicit their participation in the trial, and through links provide in the email they can agree to participate and consent through a stepped consenting process that determines their study eligibility.

Phase 5. Conduct a survey with parents and pilot test the website

Survey study

We developed a survey instrument to examine the parental vaccine decision-making process and preferences for receiving vaccine information. The design of the survey was informed by our prior qualitative work on vaccine hesitancy and the qualitative results from this study (phase 2 and 3). Specifically, the instrument contained questions on parent-provider trust, the timing of vaccine decisions, confidence in vaccine information, trusted sources of vaccine information, preferences for receiving vaccine information (e.g., prenatal class, obstetrician, pediatrician, alternative medicine provider, website, social media), and demographics. All questions were close-ended, measured either on a 5-point Likert scale, dichotomous or categorical. Questions on a Likert scale were dichotomized for the final analysis (e.g., strongly agree/agree vs. strongly disagree/disagree/neutral). The survey was pilot tested on a sample of parents (n=10) to assess the readability and clarity of survey questions. Six of the questions appeared to be poorly understood and were revised by the study team.

To identify potential survey participants, we used the KPCO electronic health record to create a stratified sampling frame of parents who either accepted, delayed, or refused vaccines for their children. We first identified all children ages 4 to 24 months between years 2009 and 2011. Each child had to be continuously enrolled in the KPCO health plan from birth until the age at which they were identified for the survey. Electronic immunization records were used to stratify children as either fully vaccinated, partially vaccinated, or unvaccinated by the age at which they were identified. A manual medical record review was then conducted on the unvaccinated and partially vaccinated children to determine if the parents had explicitly delayed or refused vaccinations for personal, nonmedical reasons. Based on the medical record review, 3 strata of parents were categorized according to their vaccine behavior: vaccine acceptors, vaccine delayers, or vaccine refusers. Surveys were sent by mail to a random sample of the

vaccine acceptors (n=500) and all of the delayers (n=227) and refusers (n=127). Surveys were mailed up to two times to each participant and no incentive was provided.

Survey analysis

Descriptive statistics were calculated for all demographic variables, including gender, race/ethnicity, marital status, education, household income, and age. Responses to dichotomized survey questions on vaccine decision-making and trust were compared across the three strata of parents with chi-square tests and multivariable polytomous logistic regression. In the logistic regression models, vaccine behavior (accept, delay, refuse) represented the multi-level dependent variable, and the dichotomized survey questions were the main independent variables, controlling for demographic characteristics. Separate models were run for each survey question, and the vaccine acceptors served as the reference category in all of the models.

An additional sub-analysis was conducted on the demographics (age, income, home clinic) of the survey non-responders to assess the potential impact of non-response bias. All analyses were conducted with SAS 9.2 (SAS Institute, Inc. Cary, NC).

Website pilot test

After a prototype website had been designed and evaluated, we conducted a pilot test with a representative group of end-users. Using similar methods described for the survey study, we identified groups of pregnant women, parents who accepted vaccines, parents who delayed vaccines and parents who refused all vaccines for their children while enrolled in the KPCO health plan. We randomly selected potential participants from each group and asked if they would be interested in reviewing and using the website. Initial recruitment included outreach by mail, email, and phone. Participants received up to 8 contacts (2 mail, 2 email, 4 phone) from the study team. Participants consented and registered for the website with study staff over the phone. The response rate was 8.9% (n=36/405). In order to determine the most efficient and effective recruitment approach, remaining recruitment activities were completed using a combination of email, mail, and phone outreach. Consent and website registration was completed with participants in two ways; either over the phone or online. In total we conducted 6 combinations of outreach and consent, which are displayed in table 1.

Table 1: Recruitment Protocol Outreach, Consent and Registration Steps

Recruitment protocol	Chronological Recruitment Steps				Consent and Registration
	1 st Contact	1 st Phone follow up	2 nd Contact	2 nd Phone follow up	
Initial Recruitment	Mail and email	2 calls	Mail and email	2 calls	Phone
1	Mail	2 calls	Mail	2 calls	Phone
2	Mail	2 calls	Mail	2 calls	Online
3	Mail	0 calls	Mail	0 calls	Online
4	Email	2 calls	Email	2 calls	Phone
5	Email	2 calls	Email	2 calls	Online
6	Email	0 calls	Email	0 calls	Online

Enrolled participants were followed for 4-6 months to monitor website activity and were administered a short survey to assess their knowledge, attitudes and beliefs about vaccinations. No incentive was provided to participate in the study. The analyses were similar to those described above for the survey study.

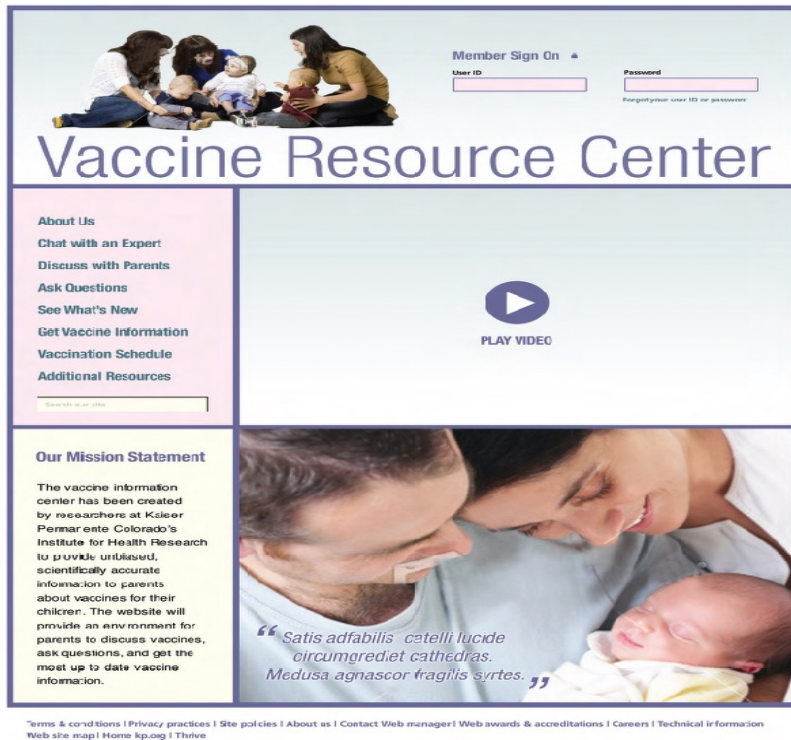
RESULTS

Phase 1. Building a prototype interactive social media website devoted to vaccines Initial development of the prototype (Design 1-3):

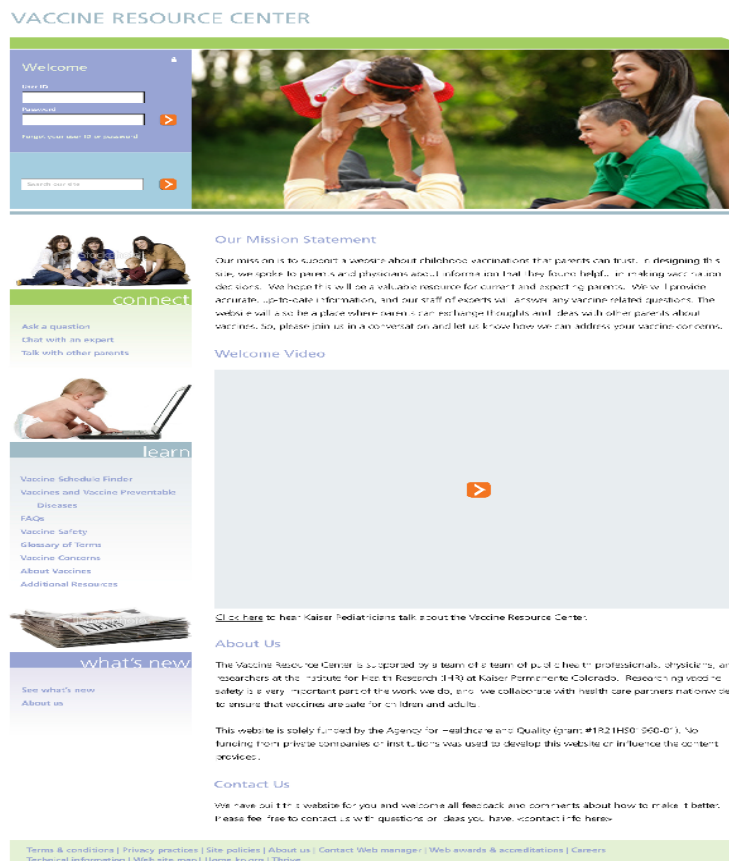
Design 1



Design 2



Design 3



Phase 2. Qualitative assessment of the website prototype

As described, we conducted focus groups and one-on-one interviews with a total of 32 providers and 23 pregnant women and parents. The objective was to use the results from these discussions to improve the design and content of the website. Using standard qualitative data collection and analytic methods, several themes emerged from these discussions. Overall, participants liked the idea of having an interactive resource where they could quickly obtain information, ask questions and engage in discussions about vaccines. In particular, many participants were pleased with the “clean” and “uncluttered” look of the website. Some participants thought the website would be easy to navigate and that information would be easy to find, unlike other vaccination websites that tend to be dense with information. New parents in particular were also encouraged by the inclusive tone of the website. They felt that our mission statement and welcome video set the tone for an environment that would be welcoming and safe – an environment where they could freely ask questions, post their concerns and not feel as though they were being pressured to vaccinate.

Despite this positive feedback, we received several suggestions on how the website could be improved. One criticism was that the graphics were perhaps “too simple” and that having to scroll up and down pages to find information may be a barrier to use. It was suggested that a more modern interface would improve its functionality and visual appeal. Another common criticism was that, while an ethnically diverse range mothers and infants were prominently displayed on the various web pages, they did not feel there were not enough images of “dads”. Both parents and providers stressed that there was not enough information on the vaccine ingredients, which is common concern among vaccine hesitant parents. Parents wanted more information on the risks of vaccination and details on the website’s sources of funding. There was also criticism that the vaccine information lacked detailed references or citations to the original sources of the information. Lastly, it was suggested that the interactive components were not displayed prominently enough on the website.

Phase 3. Qualitatively and quantitatively evaluate the website through usability testing

Two participants from each end-user group completed the usability testing (pregnant women, parents who accept vaccines, parents who delay vaccines, parents who refuse vaccines and providers). All participants were female, married had obtained a college degree or more. Eighty percent of participants were white and 20% were Hispanic. Twenty percent of participants had annual household income less than \$70,000 a year.

Four of the five tasks were completed with nearly 100% completion rate. However, the error-free rate was below 80% for both the information page and discussion forum tasks (Table 2). These tasks highlighted the need for additional links in the website, since information on particular topics was located in multiple places on the website. For example, information on the Hepatitis B vaccine (HBV) was located in the following sections: *frequently asked questions*, *vaccines and diseases they prevent*, *vaccine concerns*, and *vaccine safety*. We asked our participants to find information on why HBV is given at birth, which was located in the *frequently asked questions* section. While participants were able to easily find information on HBV, some had difficulty finding the location of this specific information. This usability error highlighted the need to add links that connected information pages with similar content. After the links were added, participants were able to find information more rapidly and accurately.

Table 2. Usability testing task results (n=10)

Task	Average time to complete	%complete	%error free
Interactive tool	74 seconds	100%	100%
Discussion forum	125 seconds	100%	20%
Information page	146 seconds	80%	10%
Blog	46 seconds	100%	80%
Live chat	46 seconds	100%	90%

Overall participants found the website easy to use (Table 3). They agreed or strongly agreed that most users could easily learn to use the website and the website functions were well integrated. The disagreed or strongly disagreed that the website was complex, that there were inconsistencies, and that it was cumbersome to use. The overall SUS score was 86.25 (67.5-95.0), suggesting the website could be navigated without difficulty.

Table 3. System Usability Scale (SUS) results (n=8)

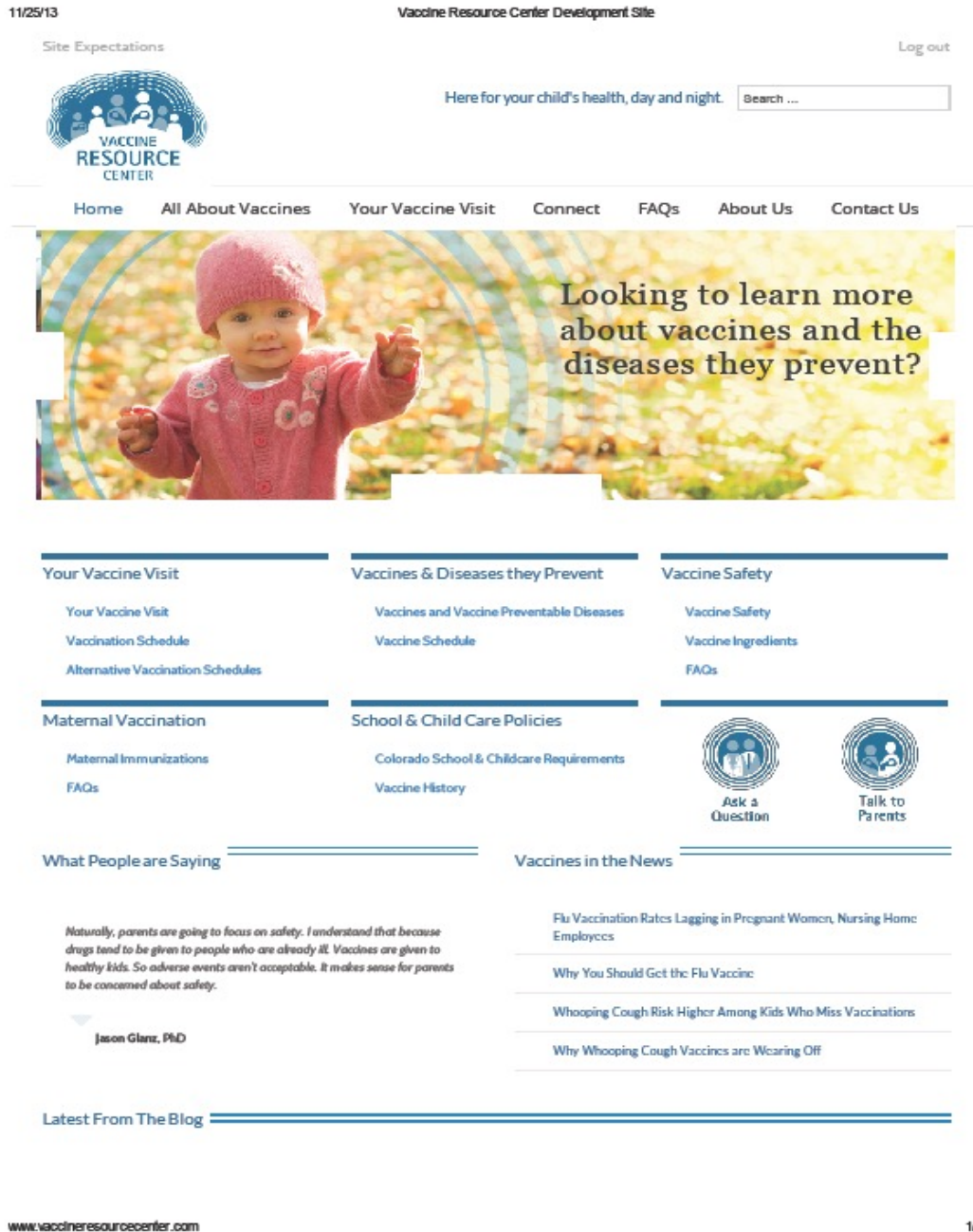
Question	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Like to use the website frequently			50%	37.5%	12.5%
Unnecessarily complex	75%	25%			
Easy to use				37.5%	62.5%
Need technical support to use the website	100%				
Functions in website were well integrated			12.5%	75%	12.5%
Too much inconsistency in this website	87.5%	12.5%			
Most people would learn to use this website quickly			12.5%	62.5%	25%
Very cumbersome to use	75%	25%			
Confident using the website		12.5%		50%	37.5%
Need to learn a lot of things before I could get going with this website	75%	12.5%	12.5%		

*Providers did not complete the SUS survey

Phase 4. Website re-design and modifications

The data collected from the focus groups and usability testing sessions were used to modify the design and functionality of website. We also updated the content and modified the layout of the information. Below is the homepage screen image of the modified website. Many of the modifications occurred during the initial phase of our randomized intervention trial.

Final Design



Phase 5. Conduct a survey with parents and pilot test the website

Survey results

The results described below have been published in the September 2013 issue of *Academic Pediatrics*(31).

Survey responses and demographics

Surveys were mailed to 854 parents, 443 (52%) of which responded. The response rate varied by vaccine group, with 47 (37%) of the vaccine refusers, 136 (60%) of the vaccine delayers, and 260 (52%) of the vaccine acceptors returning completed surveys. A majority of the parents were female, white, married, college educated, and had an annual household income greater than \$70,000 (Table 3). Three of these variables – race/ethnicity, education and household income – differed across the vaccine groups. Parents who had either refused or delayed vaccines for their children were more likely to be white than parents who accepted vaccines for their children ($P = 0.0003$). Parents who delayed vaccines had the highest proportion of households earning \$70,000 or more per year, followed by parents who accepted vaccines and parents who refused vaccines ($P = 0.007$).

Vaccine decision making

Regardless of their vaccine choices, parents reported that they first began thinking about vaccines before their child was born, either during pregnancy or before pregnancy (Table 4). In the multivariable regression analysis, parents who refused or delayed vaccinations were approximately 2-times more likely to report that they first began to think about vaccines before their child was born than parents who accepted vaccines (Table 5).

Table 4: Response to Survey Questions by Vaccine Group

Question/Statement	Proportion of Parents, %			P Value
	Refused Vaccines	Delayed Vaccines	Accepted Vaccines	
When did you first begin thinking about vaccinations?				
Before the child was born	87.2	76.4	63.6	.0007*
To what extent do you reevaluate your decision on vaccination for your child?				
Constantly/occasionally	68.1	70.6	19.8	<.0001*
I trust my pediatrician's advice on my child's vaccinations				
Strongly/somewhat agree	37.8	69.2	96.9	<.0001*
I trust my pediatrician's advice on my child's nutrition				
Strongly/somewhat agree	70.5	91.7	96.1	<.0001*
I trust my pediatrician's advice on my child's physical examination				
Strongly/somewhat agree	93.2	99.3	97.2	.08
I trust my pediatrician's advice on my child's behavior and development				
Strongly/somewhat agree	79.6	93.2	96.1	.0002*
I had enough time to discuss vaccination with my pediatrician				
Strongly/somewhat agree	80.0	71.4	75.1	.5
My child's pediatrician discussed the risks of vaccination				
Strongly/somewhat agree	26.7	41.7	51.0	.006*
My child's pediatrician discussed the benefits of vaccination				
Strongly/somewhat agree	88.9	90.2	76.0	.001*
My child's pediatrician is knowledgeable about vaccines				
Strongly/somewhat agree	54.6	74.4	79.1	.002*
How confident are you that you have the necessary information to make decisions about vaccination for your child?				
Absolutely/very confident	58.7	54.4	70.4	.005*

*Statistically significant.

Table 5: Odds Ratio Estimates for Parent Responses on Questions Related to Vaccine Decision Making and Trust/Confidence in Provider's Advice, by Vaccine Group†

Question/Statement	Parents Who Refused Versus Accepted Vaccines			Parents Who Delayed Versus Accepted Vaccines		
	Adjusted OR	95% CI	P Value	Adjusted OR	95% CI	P Value
First began thinking of vaccinations before the child was born	3.2	1.2–8.0	.01	2.3	1.4–4.0	.002*
Constantly or occasionally reevaluate vaccination decision for their child	8.1	3.8–17.4	<.0001	9.2	5.4–15.7	<.0001*
Absolutely or very confident about having necessary information to make vaccine decisions for their child	0.7	0.3–1.4	.3	0.5	0.3–0.8	.007*
Strongly disagree or disagree to trust their child's pediatrician's advice on vaccinations	35.7	10.7–119.3	<.0001	8.4	2.5–28.0	.0006*

*Statistically significant.

†OR, odds ratio; CI, confidence interval. Adjusted ORs are adjusted for demographic characteristics (age of parent, gender, race/ethnicity, education, income, and marital status).

The proportion of parents who reported that they either occasionally or constantly re-evaluate their vaccine decisions varied significantly by parental vaccination behavior. In the multivariable regression analysis, parents who refused or delayed vaccines were approximately 8-times more likely to report that they constantly re-evaluate their vaccine decisions than parents who accepted vaccines.

Trust and confidence in provider's advice

Parents tended to report a high level of trust in their pediatrician's advice on their child's nutrition, physical examination and behavior and development. However, parents who refused vaccines reported a lower level of trust in their pediatrician's advice on nutrition (70%) and behavior and development (80%) when compared to parents who either delayed or accepted vaccines (92-96%, $P < 0.0002$). Although parents who accepted vaccination reported a high level of trust in their pediatrician's vaccine advice (97%), only 69% of parents who delayed vaccines and 38% of parents who refused vaccines expressed a high level of trust in their pediatrician's advice on vaccines ($P < 0.0001$). In the multivariable regression analysis, the odds ratios for *trust* were large, but the associated 95% confidence intervals were wide. For example, parents who refused vaccines were 34-times more likely (95% CI, 9.03 – 127.13) and parents who delayed vaccines were 8-times more likely (95% CI, 2.16 – 29.72) to express a low level of trust in their pediatrician's vaccine advice than parents who accepted vaccinations.

Regarding vaccine advice, parents generally felt that they had enough time to discuss vaccination with their pediatrician but did not believe their pediatrician's vaccine information was balanced. A majority of parents reported that their pediatrician discussed the benefits but not the risks of vaccination, and these proportions varied significantly by parental vaccination behavior ($P < 0.006$).

Lastly, most parents were either very or absolutely confident that they had enough information to make vaccine decisions for their children. In the multivariable regression analysis, parents who refused or delayed vaccines were 30-40% less likely to report that they had the necessary information to make vaccine decisions than parents who accepted vaccines.

Preferences for vaccine information

The survey results below suggest that a significant proportion of all groups of parents would use a social media website to ask vaccine experts questions, to read current vaccine news stories, to express vaccine concerns, to discuss vaccines with other parents and to obtain vaccine information (Table 6).

Table 6. Selected survey results for questions about preferences for receiving vaccine information.

	Response	Acceptors (n=258)	Delayers (n=136)	Refusers (n=47)
Would likely attend a prenatal vaccination class	Strongly agree/agree	54%	70%	47%
Have other sources of vaccine information that trust more than prenatal vaccination class	Strongly agree/agree	14%	38%	75%
Would like to receive additional written materials from provider	Strongly agree/agree	54%	59%	48%
Would like to receive information from discussion with OBGYN while pregnant	Strongly agree/agree	43%	45%	30%
Would use a website to ask questions to vaccine experts	Strongly agree/agree	69%	76%	52%
Would use a website to discuss vaccines with other parents	Strongly agree/agree	27%	51%	48%
Would use a website to express vaccine concerns	Strongly agree/agree	30%	53%	93%
Would use a website to receive vaccine news	Strongly agree/agree	72%	83%	76%
Would use website to see what vaccines my child is scheduled to receive at the next provider visit	Strongly agree/agree	86%	82%	48%

Pilot study

Overall, 86 participants were enrolled in the pilot study; 18 pregnant women, 47 parents who accepted vaccines, 12 parents who delayed vaccines and 3 parents who refused all vaccines. Response rate varied by recruitment methods (See Table 7). Recruitment methods utilizing email outreach and phone interaction had the highest response rate (21.6%).

Table 7: Recruitment Protocol Response Rate

Recruitment protocol	Chronological Recruitment Steps					Response Rate
	1 st Contact	1 st Phone follow up	2 nd Contact	2 nd Phone follow up	Consent and Registration	
Initial Recruitment (n=405)	Mail and Email	2 calls	Mail and email	2 calls	Phone	8.9% (n=36)
1 (n=99)	Mail	2 calls	Mail	2 calls	Phone	14.14% (n=14)
2 (n=100)	Mail	2 calls	Mail	2 calls	Online	0% (n=0)
3 (n=100)	Mail	0 calls	Mail	0 calls	Online	0% (n=0)
4 (n=111)	Email	2 calls	Email	2 calls	Phone	21.6% (n=24)
5 (n=100)	Email	2 calls	Email	2 calls	Online	8% (n=8)
6 (n=100)	Email	0 calls	Email	0 calls	Online	4% (n=4)

On average, participants used the website on 1 occasion (0-3). Two participants sent in questions from the “ask a question” email application. One participant asked a question on the website discussion forum. The estimated patient population that would have access to the website at KPCO is 11,5000. Extrapolating these data to the entire KPCO population suggests that there would be an average of 2,406 hits and 87 questions per year.

DISCUSSION

In this mixed methods study, we built, developed and evaluated an interactive website to help parents make informed decisions about vaccinating their children. We also conducted a survey study with parents across a range of vaccination behaviors to assess their decision-making processes and preferences for vaccine information. This rigorous multi-step process provided us with valuable information on how to design and target an intervention trial to measure the website’s effectiveness.

The initial phases of our study focused on developing vaccine information and risk communication messages targeted toward vaccine hesitant parents. We also created a simple website design so users could find the information with minimal effort. The focus groups and usability testing showed that we accomplished our goals; however, they also showed that it is important to build a tool that is visually appealing with modern technologies that the target end-users are familiar with. The website must have a professional appearance to establish credibility and compete with the numerous publically available resources that present misinformation on vaccines.

Our survey study showed that it is important to consider the timing of vaccine decision-making when designing web-based interventions to address parental vaccination concerns. While more than half of all parents in our study said they began thinking about vaccines before their children were born, the proportion increased significantly across the groups of parents that accepted, delayed or refused vaccines for their children. This suggests that concerned parents who go on to delay or refuse vaccines start to make their vaccine decisions earlier than parents who accept vaccines. It is therefore reasonable to assume that the latter group relies more heavily on their pediatrician for vaccine advice, while the former tend to seek other sources of vaccine information. These results suggest that web-based, social media interventions may be more effective if designed to target vaccine hesitant parents earlier in the decision-making process.

In addition to starting their decision-making early, parents who refused or delayed vaccines in our survey study were more likely to report that they occasionally or constantly re-evaluate their vaccine decisions than parents who accepted vaccines. Prior research has suggested that parental vaccine hesitancy may be attributed, in part, to a cognitive bias known “omission bias”, where the harm resulting from inaction (not vaccinating) is considered to be more acceptable than harm resulting from action (vaccinating) (39-43). While omission bias may influence vaccine behaviors, our data shows that parents also fear the harm that may result from their inaction, thus leading them to constantly wrestle with their vaccine decisions. A social media intervention is well-suited to address this issue because concerned parents should be engaged at multiple time points as they contemplate the consequences of their decisions to forgo vaccination for their children.

Across all vaccine behavior groups, parents in the survey study reported that their pediatrician was much more likely to discuss the benefits of vaccination than the risks. Vaccine hesitant parents in particular appeared to be looking for more “balanced” vaccine information from their physicians. Although these parents were clear about wanting physicians to emphasize the risks of vaccination in their discussions, our survey did not specifically assess what types of adverse reactions they wanted described. For

example, physicians may want to present the risks of minor acute conditions, while parents may want to hear about potential long-term serious outcomes. Clearly, there needs to be additional study on how tools to address vaccine hesitancy can effectively convey balanced vaccine information.

Although web-based social media represents a potential cost effective tool to address vaccine hesitancy, it requires significant resources to develop and maintain. To be effective, the content must be current, blog entries have to be consistently updated, and the forums must be rigorously monitored and moderated. Most importantly, an interactive web-based resource requires a dedicated team of content experts who can review content and respond to parental concerns with accurate information in a timely manner. We will be conducting a formal cost-effectiveness analysis in our AHRQ-funded randomized intervention trial that is currently underway.

For a social media website to be effective, it is important to establish trust with the target end-user. Our focus group and usability testing sessions demonstrated numerous ways in which trust can be established. For example, providing detailed documentation on the sources of our vaccine information was important to the participants. It was also stressed that we should prominently display the source of our funding; the participants were quite pleased that the website was funded by AHRQ rather than a pharmaceutical company. Participants emphasized that the risks of vaccination should be clearly described in the website's content and that information on the study and study team be easily accessible. All of these areas have been addressed on the current version of the website, which we believe will improve our credibility and in turn increase the likelihood that it is an effective tool for reducing parental vaccination concerns.

Participant recruitment was a significant challenge in our pilot study, and we believe there are several reasons for this. One, because this was a developmental grant with limited resources, we did not provide monetary incentive, such as a gift card, to solicit participation in the study. Two, we attempted to recruit many parents with children older than 6 months of age, which is after they have likely made their vaccine decisions. Three, we learned that our online process for consenting into the study and completing the survey was somewhat inefficient and tedious for the potential participants. Lastly, our developmental budget did not allow us to apply the most rigorous methods for participant contact and recruitment. For our current intervention trial, we are providing incentive to participants, our online consenting and survey process has been streamlined, we are recruiting pregnant women, and we are contacting potential participants with a combination of letters, email, postcards and phone calls to improve study recruitment.

We have demonstrated in this developmental grant that an interactive social media website has the potential to be an effective tool for addressing parental vaccination concerns. Such an intervention, however, poses numerous challenges, including establishing trust, making it cost-effective and improving methods for recruitment. We believe our current AHRQ-funded randomized intervention trial will address these challenges.

List of Publications and Products:

Glanz JM, Wagner NM, Narwaney KJ, Shoup JA, McClure DL, McCormick EV et al. A mixed methods study of parental vaccine decision making and parent-provider trust. *Acad Pediatr* 2013; 13(5):481-488.

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